

Consumer-Directed Transformation to a Recovery-Based Mental Health System

by

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Executive Summary

Today's mental health system has failed to facilitate recovery of most people labeled with severe mental illnesses, leading to increasing expressions of dissatisfaction by people using services, their families, and administrators. Only a fundamental change of the very culture of the system will ensure that the changes made in policy, training, services, and research will lead to genuine recovery. In accordance with the President's New Freedom Commission on Mental Health report, mental health consumers and survivors, representing diverse cultural backgrounds, should play a leading role in designing and implementing the transformation to a recovery-based mental health system.

This paper provides an outline of how consumers/survivors can catalyze a transformation of the mental health system from one based on an institutional culture of control and exclusion to one based on a recovery culture of self-determination and community participation. At the national policy level, this paper recommends that consumers develop and implement a National Recovery Initiative. At the State and local policy levels, State and local recovery initiatives are recommended. On the direct service level, the paper provides a road map for developing services, financing, and supports that are based on self-determination and recovery.

A recovery-based mental health system would embrace the following values:

- Self-determination
- Empowering relationships based on trust, understanding, and respect
- Meaningful roles in society
- Elimination of stigma and discrimination

Changing the mental health system to one that is based on the principles of recovery will require a concerted effort of consumers and allies working to bring about changes in beliefs and practices at every level of the system. The building of these alliances will require the practice of recovery principles of trust, understanding, and respect by all parties involved.

GOAL A Consumer/Survivor-Led Transformation from an Institutionally Based System to a Recovery-Based System

Objective 1 Transform the system to one based on a recovery culture through a consumer/survivor-led National Recovery Initiative (NRI) and State Recovery Initiatives (SRI).

Step 1.1 Consumer/survivor leaders will set up a National Recovery Initiative Steering Committee, which will establish an NRI Agenda and assist the SRIs to establish theirs. Once the NRI Steering Committee is established, it will

- Develop a National Recovery Initiative Action Agenda.
- Play a role in the implementation of the New Freedom Commission report at the Federal and State levels.
- Establish subcommittees on recovery education, recovery policy development, recovery-based evaluation and research, and development of recovery-based services and supports.

Step 1.2 The NRI Subcommittee on Recovery Education will launch a nationwide pro-recovery, anti-stigma education campaign

Step 1.3 The NRI Subcommittee on Policy will develop and synthesize model recovery policies as well as materials for training consumers in board participation.

Step 1.4 The NRI Subcommittee on Recovery-Based Evaluation and Research will develop materials and train consumers in carrying out evaluations of the performance of mental health systems.

Step 1.5 The NRI Subcommittee on Recovery-Based Services and Supports will supply the networking and technical assistance needed to help in the further development of peer-run services.

Objective 2 With consumer direction, transform the mental health system to a system of expanded choices of recovery-based services and supports.

Step 2.1 Shift to person-centered planning.

Step 2.2 Shift to financing mechanisms that support increased consumer control.

Step 2.3 Expand the range of choices of services and supports available by creating roles for peers in service delivery and support.

Background

Although many people with mental illnesses have been moved from State institutions to community settings, most have not recovered. They are living in the community, but they are not integrated into the community in a meaningful manner. Although State hospital patients have been transported to community settings and been renamed consumers, the institutional thinking of all stakeholders is impeding their recovery. This institutional thinking persists in the application of an outdated, classical medical model that describes serious mental illnesses as permanent, biological diseases. Institutional thinking considers recovery unlikely, and “good” outcomes are considered to be lifetimes of maintenance on psychiatric drugs, residence in halfway houses or other supervised settings, and repetitive days of mindless “activities,” dead-end, below minimum wage jobs, or work in sheltered workshops. This system has led to huge costs for maintaining this population, hopelessness for people diagnosed with mental illnesses, political inertia, and a lack of interest on the part of many professionals for dealing with a population deemed to be incurable. In short, we have taken the people out of institutions but we have not taken institutional thinking out of the people. Institutional thinking persists in all societal thinking about mental illness and severely hampers efforts to facilitate recovery.

Since empowerment, hope, and self-determination are repeatedly cited as the keys to people’s recovery (Ahern & Fisher, 2001; Anthony et al., 2002; Zinman, 2002; and Chamberlin, 2003), it appears that the underlying institutional medical culture of the present system, with its overemphasis on the narrowly defined version of the medical approach, is actually interfering with recovery. Recently, consumers/survivors, administrators, and families have united in the conviction that the mental health system needs a fundamental transformation of its mission and values to a system based on recovery. In this paper, we present a road map for consumer-driven transformation to a recovery-based system that can act as a unifying action plan for citizens and government alike. No longer can people with mental illnesses wait for government to lead the way to a new system. The leadership for this transformation needs to be taken up by consumers/survivors, families, and other advocates, in partnership with government and mental health authorities.

Many voices have been calling for change, including segments of the professional community, families, political leaders, and, perhaps most important, diagnosed people themselves, many of whom have refused to accept the limited roles they were expected to fulfill. These voices for change have recently received support from the President’s New Freedom Commission on Mental Health, whose report called for a transformation of the mental health system to one based on the principles of recovery, as stated in its vision: “We envision a future when everyone with a mental illness will recover” (*Achieving the Promise: Transforming Mental Health Care in America. Final Report*, 2003, which hereafter will be referred to as the Commission Report, p. 1). The

report also states that “care must focus on . . . facilitating recovery, and on building resilience, not just on managing symptoms” (Commission Report, p. 5).

Other government studies have reached similar conclusions. The Veterans Administration Action Agenda (2003) has called for recovery to be a central principle in the transformation of Veterans Administration (VA) services and supports by recommending that the VA do the following:

- Adopt the Recovery Model in VA mental health programs nationwide.
- Develop VA-adapted Recovery implementation tools as the basis for a national rollout.
- Involve veteran consumers and families in educating staff, veterans, and family members on recovery.

The Surgeon General’s report on mental health (U.S. Department of Health and Human Services, 1999) and the National Council on Disability report, *From Privileges to Rights* (National Council on Disability, 2000), also highlight the importance of having people who have recovered from mental illnesses play an active role in the policies and services of the system.

Key Issues and Discussion

Culture change needed. Only a fundamental change of the very culture of the system will ensure that the changes made in policy, training, research, and services will lead to genuine recovery. Consumers/survivors must play a leading role in designing and implementing this transformation. Otherwise, we will see people who have recovered playing a secondary role with their work fit into the existing system, rather than their work leading the transformation to a recovery-based system.

An example is provided by a mental health center that pointed proudly to their use of peer counselors. However, rather than being asked to use their personal experience to serve as role models and guides to clients in earlier stages of recovery, these “peer counselors” were given the job of monitoring medication. In other words, they had to adapt to the existing institutional culture of dependency instead of leading the transformation to a system based on recovery.

In addition, the recovery culture needs to be culturally competent as recommended in the Surgeon General’s report on Mental Health: Culture, Race, and Ethnicity (US DHHS, 2001). The existing institutionally based system is narrow in its scope, thereby leaving little room for minority cultures. A recovery-based system would be more accepting and understanding of people from a variety of backgrounds.

The Western New York Care Coordination Program (WNYCC) provides a further illustration of the importance of culture change to influencing lasting transformation of the system. Their Web site states:

The Western New York Care Coordination Program is a collaborative initiative by six County governments, the New York State Office of Mental Health, providers, and consumers to transform community services systems serving people diagnosed with serious mental illness. The goal of the program is to create systems that are responsive to the interests of consumers, ensure access to high quality services, and promote recovery. . . . The Steering Committee identified culture change as the critical first step to system transformation. This begins with the composition of the Committee and its collegial approach to development and implementation of the program. A major initiative is education and training programs in all participating counties for all participating providers and consumers about the principles of person-centered planning, consumer-directed care, and recovery. . . . Despite the care taken to develop a template for individual service planning that focused on the interests of individual recipients, a review of the first set of individual service plans developed by care coordinators revealed little change from the ‘provider knows best’ case management system.

(www.carecoordination.org/prog_description.shtml)

Therefore, care must be taken to introduce cultural change training, which emphasizes recovery and person-centered planning, into the initial steps of system transformation. Most important, people who have recovered should lead this training.

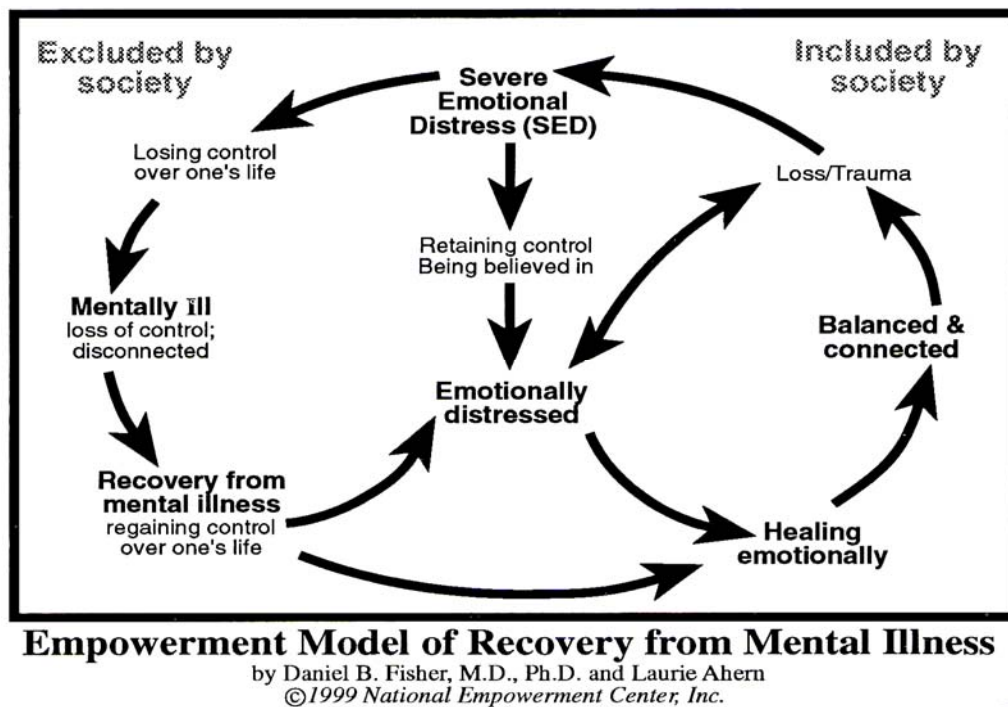
Definition of recovery. In a recovery culture, peer support will be seen as the central focus of the services and supports. Peers can transform both the individuals they are helping and those around them. It will be important for consumers/survivors to take the lead because they have the greatest commitment to real change. Although the term “recovery” has come into the lexicon of Federal, State, and local reports and plans, there is a concern among consumers/survivors that the meaning of recovery has been subverted.

The first example of what we call a limiting version of recovery appeared in the rehabilitation literature of the early 1990s (Anthony et al., 2002). These authors contend that mental illness is analogous to a spinal cord injury. According to this limiting version of recovery, people with mental illnesses, like people with a spinal cord injury, can learn to cope with their illness but they will never fully recover from a mental illness.

On the other hand, consumers/survivors and researchers have experienced, researched, and written about complete recovery from mental illnesses. (Harding et al., 1987; Karon & VandenBos, 1981; Ahern & Fisher, 2001). This we will call genuine recovery. The National Empowerment Center (NEC) has described the path to genuine recovery—the empowerment model of recovery. According to this model, people with mental illnesses can completely recover by taking control of the major decisions of their lives and thereby assuming or resuming major social roles. We emphasize the importance of this distinction because it lies at the heart of the transformation of the system. If the vision of recovery really means limited recovery, the services will still be designed to control a consumer’s major decisions for the rest of his or her life. A system based on a goal of limited recovery is a system with no exit points. It is a system that is always run from the top down by administrators, doctors, and other clinicians who perpetually make decisions for the consumer.

However, it is important to emphasize that, in the NEC definition of full, genuine recovery, people may continue to experience symptoms or may choose to use medication. The hallmark of genuine recovery is the individual regaining control of his or her own life and filling valued social roles. The Empowerment Model illustrated in Figure 1 is based on the research findings that genuine recovery is possible for most people labeled with mental illnesses (Ahern & Fisher, 2001). Given the right mix of resources, relationships, and attitudes, people with mental illnesses can fully recover by (re)gaining control of the central decisions of their lives, learning to live with intense emotions, and developing the skills and relationships needed to establish a major social role.

Figure 1



Most people begin life at the right side of the model (Figure 1), balanced and whole. However, we all suffer trauma and loss, which leads to emotional distress and feelings of fragmentation and not being whole. Through coping strategies and social supports, most people are able to heal emotionally and indeed develop a stronger sense of self. Sometimes, however, a major trauma or loss, such as a move to college or the loss of a loved one, can lead to severe emotional distress. At that point (at the top of the diagram) it is crucial that sufficient noninstitutional supports and coping strategies be available to allow the person to heal. During this period, it is also vital that the person retain his/her connections with his/her community and as much control over his/her life as possible. In the absence of supports, such as people who believe in him/her, housing, finances, and coping strategies, the person's life and controls are taken over by institutional mental health systems and programs, and she or he is labeled severely mentally ill. Once a person is labeled with mental illness, he or she must recover not only from the severe emotional distress, but also from the role and identity of a person with mental illness. The label not only relegates people to a low status and diminished rights, but also eats away at their confidence and initiative to pursue dreams and to lead full lives of their own choosing. Consumers/survivors have united around the goal of genuine recovery as outlined in this Empowerment Model.

The report of the Subcommittee on Consumer Issues to the New Freedom Commission (www.mentalhealthcommission.gov) described genuine recovery very well:

Mental health research shows that people can and do fully recover, even from the most severe forms of mental illness. Most fundamentally, recovery means having hope for the future, living a self-determined life, maintaining self-esteem, and achieving meaningful roles in society. Most consumers report they want the same things other people want: a sense of belonging, an adequate income, a way to get around, and a decent place to live. They aspire to build an acceptable identity for themselves and in the community at large. These are the essential ingredients of recovery from mental illness.

Recovery as an organizing principle. An emerging literature on the success of the recovery approach comes from the self-help movement, testimony of consumers, the psychiatric rehabilitation community, and research. Public and private sectors of the mental health community are initiating recovery-based programs, services, and self-help technologies to overcome the barriers faced by people living with mental illnesses in America. Recovery is an organizing principle for mental health services, programs, and supports that is based on consumer values of choice, self-determination, acceptance, and healing.

For recovery to take place, the culture of mental health care must shift to a culture that is based on self-determination, empowering relationships, and full participation of mental health consumers in the work and community life of society. To build a recovery-based system, the mental health community must draw upon the resources of people with mental illnesses in their communities.

It is widely recognized that changing the mental health system to be more responsive to consumer needs requires the participation of consumers at all levels of policy planning and program development, implementation, and evaluation. Meaningful involvement of consumers in the mental health system can ensure they lead a self-determined life in the community, rather than remaining dependent on the mental health system for a lifetime. A recovery-oriented mental health system embraces the following values:

- Self-determination
- Empowering relationships
- Meaningful roles in society
- Eliminating stigma and discrimination

Recovery Initiative Action Plan

We are proposing in this paper a Recovery Initiative Action plan, with the following major goal and objectives:

GOAL: A Consumer/Survivor-Led Transformation from an Institutionally Based System to a Recovery-Based System

To insure that mental health services are truly empowering and recovery focused, attention must be paid to the underlying values of each service (e.g., hospitalization, crisis intervention, housing, rehabilitation services, employment services, etc.). Services that are focused on symptom management or maintenance, for example, must give way to services that stress movement, development, and change (in other words, are recovery-based). Services must provide mechanisms for community integration and promote opportunities to live in ways that nondisabled people live.

It is clear that a massive shift in philosophy, accompanied by changes in funding mechanisms, will be necessary to implement successful self-determination approaches that maximize the ability of people with psychiatric disabilities to gain control of their lives. In the next section, we will describe a proposal for making the necessary shifts to a recovery culture so that the kinds of new programs and funding mechanisms described above can flourish.

Objective 1: Transform the system to one based on a recovery culture through a consumer/survivor-led National Recovery Initiative (NRI) and State Recovery Initiatives (SRI).

The New Freedom Commission report recommends that the system “involve consumers and families fully in orienting the mental health system toward recovery . . . Local, State, and Federal authorities must encourage consumers and families to participate in planning and evaluating treatment and support services. The direct participation of consumers and families in developing of a range of community-based, recovery-oriented treatment and support services is a priority” (Commission Report, p. 37). “Every mental health education and training program in the Nation should voluntarily assess the extent to which it . . . engages consumers and families as educators of other health care providers” about the concepts of recovery (Commission Report, p. 75).

Over the past two decades, mental health consumers/survivors have started to build a national presence within the public mental health sector, with growing numbers now participating in research and evaluation (Van Tosh, Ralph, & Campbell, 2000) and taking leadership roles in policy and administration of public mental health services (McCabe & Unzicker, 1995). They have led efforts to determine housing preferences (Tanzman, 1993), to define outcome measures (Campbell, 1997; Trochim, Dumont, & Campbell, 1993), and to develop partnerships models with public mental health

professionals (Campbell, 1996). Consumers/survivors have carved out an expanding role in lecturing, conducting grand rounds, teaching continuing education classes, and offering workshops at national professional conferences. In 1993, consumer-practitioners and psychiatrists engaged in a dialogue in New York regarding coping strategies and recovery from mental illness (Blanch, Fisher, Tucker, Walsh, & Chassman, 1993).

To truly transform a system, it is necessary to effect changes at all levels. The Commission's recommendations provide the roles for consumers to catalyze such a transformation at all levels and activities of the system. Consumers are the best agents to foster the needed changes. In its March 2003 report, the Consumers' Issues Subcommittee of the New Freedom Commission proposed the concept of a National Recovery Initiative: "In order to facilitate recovery from mental illness, the Subcommittee urges Federal, State, and local governments to together develop a National Recovery Initiative that promotes consumers' self-determination at both the collective and individual levels of recovery" (www.mentalhealthcommission.gov).

The policy options that follow comprise the key components of the proposed National Recovery Initiative. This idea has captured the imagination of many consumers/survivors across the country because it gives substance to a unifying principle. Recovery inspires consumers to be involved in transforming the system and in their own lives in a manner that the present system has failed to do. A National Recovery Initiative also gives consumers/survivors an opportunity to exercise a degree of control in their lives, which was never before apparent. The vision of recovery has unified consumers/survivors as never before. This is a proposal to form temporary committees centered on shared recovery values and shared implementation rather than a proposal to form a permanent national organization.

Step 1.1 Consumer/survivor leaders will set up a National Recovery Initiative Steering Committee, which will establish an NRI Agenda and assist the SRIs to set up their agendas.

Establish an NRI Steering Committee. The purpose of this steering committee would be to recommend national goals, policies, and actions for carrying out the steps outlined below. The committee would also monitor progress towards these goals through an evaluation component. Since the theme of "nothing about us without us" is a key principle throughout the consumer/survivor community, it will be important to have all the significant segments of that community represented from the outset.

Consumers/survivors from diverse cultures have rarely had a voice in mental health policies. Therefore, from the outset, it will be important to assure that representatives from diverse cultures are actively engaged at the table and that attention is given to culturally responsive materials. In addition, it would be important to be inclusive of people from sexual and gender identity/expression minority communities. The criteria would include the following:

- State and/or national level experience with the development of mental health policies
- An ability to work with a variety of people from a variety of backgrounds
- An understanding and acceptance of the basic recovery premises outlined in the New Freedom Commission report
- Representation of the various philosophical views, geographic regions, ages, ethnic groups, and sexual and gender identity/expression minority communities

A congress of 40–50 consumer leaders would be the mechanism through which the steering committee would be established. Although ideally such a congress should take place in person, several teleconferences could be used instead. A primary function of this steering committee would be the development of a National Recovery Initiative Action Agenda. This agenda would consist of a section on the process for bringing such an initiative into being and a section on content guidelines.

Develop the National Recovery Initiative Action Agenda. The New Freedom Commission's Subcommittee on Consumer Issues started the process of developing an NRI Action Agenda in 2002–03. A paper on consumer issues was generated from feedback from consumer leaders at Alternatives 2002, the 2002 meeting of the National Association of Rights, Protection, and Advocacy (NARPA), and leaders at a meeting of the National Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA) in 2002. The next step is for the NRI Steering Committee to develop an action agenda to carry out the goals established through the Subcommittee.

Since its appearance in 2003, the idea of a National Recovery Initiative has captured the imaginations of numerous consumer leaders. This theme has been capable of unifying factions of the consumer movement and the family movement around a common, positive concern. The proposed contents of the Initiative were outlined in the Subcommittee's report, and are divided into two levels of consumer activity: collective (systemic) and individual self-determination.

The Subcommittee recommends increasing collective consumer self-determination by ensuring consumers' significant participation in the development of a National Recovery Initiative. This initiative would inform policy, evaluation, research, training, and service delivery at local, State, and national levels in all systems integral to recovery from mental illnesses. The Subcommittee urges Federal, State, and local governments to employ consumers in leadership roles in the development of a National Recovery Initiative.

The Subcommittee also urges the mental health system at the Federal, State, and local levels to increase individual consumer self-determination by helping people with mental illnesses to acquire the self-management skills needed to manage their own lives. To accomplish this, we urge a shift from traditional services to recovery planning services, such as peer support services and services provided by independent living centers (www.mentalhealthcommission.gov).

The NRI Steering Committee would have an interactive Web site on which it would post its membership and its agenda, and on which it would receive feedback. Additional methods of dissemination and dialogue would be provided as well, in recognition that Web access is not universal, and is probably more limited for consumers, and even more so for consumers who are members of ethnic and racial minority groups.

Play a role in implementation of the New Freedom Commission report at the Federal and State levels.

The commission recommends that the fragmentation in funding and services be reduced by the development of a Federal mental health policy across department lines. For instance, though SAMHSA is the lead agency in Federal mental health policy, it plays a minor role in financing compared to the Centers for Medicare and Medicaid Services, the Social Security Administration, the Department of Housing and Urban Development, the Rehabilitation Services Administration, the National Institute of Mental Health, and the Department of Veterans Affairs. The NRI Steering Committee could play a valuable role in assisting these agencies to coordinate the changes in funding and regulations needed to facilitate the shift to a recovery-based system. If the NRI could have representation on the strategic planning bodies of these agencies, it would allow for representation of a broad cross-section of consumers nationally. In addition, the NRI Steering Committee could give support and coordination to transformation at the State levels. The steering committee could facilitate the establishment of a Statewide Recovery Initiative (SRI) in each State.

Establish subcommittees on recovery education, recovery policy development, recovery-based evaluation and research, and development of recovery-based services and supports.

These subcommittees would be selected by the NRI Steering Committee and would lead the systemic transformation to a recovery culture. They would educate decision makers and the public about recovery and their role in setting policies consistent with a recovery culture, in carrying out system evaluation to ensure that the changes made promote the transformation to recovery, and in developing recovery-based peer-run services and supports. These subcommittees would use an NRI Web site to interact with constituents.

Step 1.2 The NRI Subcommittee on Recovery Education will launch a nationwide pro-recovery, anti-stigma education campaign.

The present mental health system is a top down hierarchy. The culture of the present system relies on these top decision makers: administrators, funders, clinical directors, and mental health professionals. These are the people who need to buy into a shift to a recovery culture. These are the people who need to see that sharing their decision making power will make the system function better and facilitate recovery of consumers. These are the people who need to inspire and guide their service providers to realize

that a transformation to a recovery-based system is desirable. To meet this need, the steering committee would select a subcommittee on recovery education, consisting of representatives of the steering committee and nationally recognized recovery educators. In addition, a national panel of consumer leaders with experience in providing recovery education will be convened to develop a national recovery curriculum. It would be important to ensure that the curriculum is culturally competent around the needs of diverse ethnic, sexual, and gender communities.

Since personal contact with people who have firsthand experience with recovery is generally the most effective tool for transforming the hearts and minds of people entrusted with mental health policy direction and service delivery, it is proposed that consumers guide a large-scale recovery education project in consultation with top-level decision makers. Bassman and Penney established a viable model for such an educational initiative in New York (Bassman, 2000) by pairing consumer recovery educators with local consumers. These teams educated hospital staff on the principles of recovery. The New York Association of Psychosocial Rehabilitation (Rosenthal, personal communication) has used a similar model and, in addition, educates the community. Some States such as California have placed a high priority on recovery education and have relied on national and local educators. Undoubtedly, it would be necessary to start by having the present recovery educators training and mentoring emerging consumer leaders to build capacity. This could be carried out by regional training conferences. These recovery educators could teach recovery competencies to all persons who provide assistance to consumers. This recovery training could also serve to reduce stigma and discrimination among community residents. A pro-recovery message is usually the best anti-stigma approach.

Another responsibility of this subcommittee would be the development, in conjunction with the consumer technical assistance centers, of a Web site and library of self-help materials. In addition, this Web site could provide information on the four areas which the Commission Report highlighted as needing extra attention: disparities for minorities in mental health, the effects of long-term medication use, the effects of trauma, and problems of acute care (Commission Report, 2003, pp. 76–77).

Step 1.3 The NRI Subcommittee on Policy will develop and synthesize model recovery policies as well as materials for training consumers in board participation.

To play a significant role in policy development, consumers/survivors need to understand recovery principles, have ideas of policies for which they could advocate, and have an understanding of evaluation methodologies, so that the effectiveness of the instituted policies could be determined. Many of these materials already exist in different locales. The job of the committee would be to bring together the best materials and agree on a toolkit for consumer participation in policy development. Consultants can help, but consumers need to play a lead role to ensure that the materials focus on genuine recovery and are presented in formats and languages that are accessible at a

variety of educational levels and are responsive to cultural differences. In addition to considering the needs of people of varying race and ethnicity, training materials need to consider the needs of people with disabilities other than mental illness. For example, this might include the use of material and training accommodations (e.g., Braille, large print, sign language interpretation, cassettes, and CDs).

This committee would also prepare ongoing policy analysis and supply the information to the Steering Committee to assist them in participating in national policy formation.

Step 1.4 The NRI Subcommittee on Recovery-Based Evaluation and Research will develop materials and train consumers in these areas.

This subcommittee will establish a toolkit for the evaluation of programs to determine the degree to which new programs reflect recovery values and practices. Consumer-run evaluation teams have already shown their ability to evaluate mental health programs in Ohio, Pennsylvania, Georgia, Florida, South Carolina, and Massachusetts (Campbell, 1997). Consumers are more candid when speaking to fellow consumers. Evaluations would supply valuable information to the policy setting committee. In addition, more attention and resources need to be allocated to consumer-driven research in the area of recovery. The Commission Report highlighted this need. This activity will require the funding and training of consumer researchers. These researchers should be in a position to develop baseline data that can be used as the foundation for future collection and evaluation of evidence-based data on recovery and recovery-based services.

Step 1.5 The NRI Subcommittee on Recovery-Based Services and Supports will supply the networking and technical assistance needed to help in the further development of peer-run services.

Consumers are uniquely suited to further develop peer-run services. It is very difficult for even the most well-intentioned professionals to start peer-run services. The shared experience of being labeled and living on disability benefits, the role modeling afforded by one's own recovery, and the decrease in stigma and discrimination all make consumers much more open to participating in peer-run services than in professionally run services. The subcommittee would work closely with the National Technical Assistance Centers to survey the statewide consumer organizations, which in turn would assess the peer support groups and determine what they need for further development.

The following section will elaborate in more detail the topic of implementing self-determination at the services and supports level.

Objective 2 With consumer direction, transform the mental health system to a system of expanded choices of recovery-based services and supports.

The existing mental health system is based on an institutional medical model that views mental illness as a lifelong condition from which it is impossible to fully recover. As a result, service users have only limited opportunities to fulfill any role other than that of passive recipient of whatever services treating professionals determine they should receive. "Choice," in this context, is limited to, at best, selecting within a predetermined set of options. Even when service users are allowed such limited choices, they are frequently overruled on the basis of clinical judgment. The implicit message is that service recipients are incapable of assessing or acting in their own best interests, and that disagreement with treating professionals is evidence of symptomatology rather than of self-assertion and self-determination.

A recovery-based mental health system, on the other hand, would start from an entirely different premise. Each person entering the system would be viewed as undergoing a period of temporary distress and disorganization, from which he or she is expected to recover, given appropriate supports. Each service user would have the full opportunity to select those services and supports, which, in his/her evaluation, would best meet his or her needs at that time.

For a person entering the system in acute crisis, such needs would most likely center on providing safety and security as defined by the individual. This probably would involve a small, home-like setting (or the person's own home), with helpers of his or her choice ensuring that basic needs (such as nutritious food and adequate sleep) were met. As the person emerged from an acute state, the range of options and choices would enlarge, based on assisting the individual to resume former roles or move on to new ones. Peer support options should be offered as early as possible on a one-on-one basis with the goal of moving the person into mutual support. The peer specialist could help the consumer negotiate the systems involved in recovery by providing insider knowledge, hope, and role modeling. Helpers would include the full array of mental health professionals, as well as peer supporters and natural supports (family and friends).

At present, there are only a small number of adequately funded consumer-run programs. Even when mental health authorities have funded small projects for peer support, these are seldom integrated well into the existing mental health system, are usually viewed as adjuncts and "frills," and still leave only very limited avenues for meaningful consumer involvement.

Currently, only a narrow range of clinically based services is reimbursable under Medicaid for adults with psychiatric disabilities living in the community. These programs are designed by clinicians and tend to be medically based, with little relevance to

concepts of independent living, consumer choice, or recovery. Consumers can increase their control by writing their own individualized recovery plan, which can then form the basis for which supports and services would be covered. Consumers as individuals need to lead the transformation of their own lives, becoming self-determining adults by exerting maximum control in the choice and provision of the services and supports they need to integrate into the community. The Commission pointed out that a “Medicaid Cash and Counseling Demonstration waiver program that focuses on people with physical disabilities, developmental disabilities, and older adults confirms what many have long suspected. . . . when compared to traditional agency-directed personal care services, consumer-directed services resulted in higher client satisfaction, increased numbers of needs being met, and equivalent levels of health and safety in a large population of people with disabilities” (Commission Report, 2003, p. 35).

Several States have experimented with such cash and counseling or self-determination projects. Financing arrangements where money follows the person have been successful for those with developmental disabilities. Medicaid recipients in Arkansas with developmental disabilities who direct their own supportive services were significantly more satisfied and had a higher quality of life than those receiving services through a home care agency (Foster et al., 2003). However, for people labeled with mental illnesses, only Florida has succeeded in its attempts, and only on a small scale.

Dr. Thomas Nerney (Nerney, 2004) has described the five principles of self-determination as follows:

- *Freedom*—the opportunity to choose where and with whom one lives as well as how one organizes all important aspects of one’s life with freely chosen assistance as needed;
- *Authority*—the ability to control some targeted amount of public dollars;
- *Support*—the ability to organize that support in ways that are unique to the individual;
- *Responsibility*—the obligation to use public dollars wisely and to contribute to one’s community; and
- *Confirmation*—the recognition that individuals with disabilities themselves must be a major part of the redesign of the human service system.

Nerney noted how these ideas of self-determination are being incorporated into the care of people with a variety of disabilities:

In the last decade public policy for individuals with physical and cognitive or intellectual disabilities has gradually been coalescing around several important themes. These themes all lead toward greater recognition of community participation, income production or work, control over resources, and leading meaningful lives that resemble in all important respects the aspirations and ambitions that all Americans have for them. This is not to say that these goals have been realized or that the impetus to achieve them does not vary from State to State. (Nerney, 2004)

In Michigan in 2003, the Michigan Department of Mental Health issued this directive:

Persons who rely on the public mental health system for necessary supports and services must have access to meaningful options from which to make choices, and be supported to control the course of their lives. Arrangements that support self-determination must be sponsored by the public mental health system, assuring methods for the person to exert control over how, by whom, and to what ends they are served and supported. (Nerney, 2004)

Despite this policy goal, Nerney has found that such policies fall short in assisting people with mental illnesses: “As Michigan attempts to valiantly implement self-determination, people with psychiatric disabilities still fall through the cracks, experience homelessness in great numbers, and live in abject poverty in greater numbers than any other population” (Nerney 2004).

The experience in Florida has been more successful, though it has been provided to just 100 consumers. The Florida Self-Directed Care program describes itself as

...an approach to providing publicly funded behavioral health care services wherein the individual has a high degree of self-determination in choosing services and providers necessary for recovery from mental illness. AMHSDC [Adult Mental Health Self-Directed Care Program] assists in funding mental health treatment and support services to adults who have serious mental illness, allowing the individual to control the public mental health funds allotted for his/her treatment and to directly purchase the services from the vendor of choice. Individuals are offered independent advice and guidance in securing the services they need to begin the recovery process. (www.floridasdc.info)

The AMHSDC program allows individuals with a severe and persistent mental illness to take more personal control of their recovery. It allows them to become less passive and more proactive in the treatment and recovery process. Those who have the necessary motivation and ability to do so are able to receive the treatment that, in their own judgment, is best for them. Each participant's recovery progress is being tracked carefully in an effort to determine what potential value lies in this approach.

Participants in the AMHSDC program choose from a variety of community-based providers that may or may not already be a part of the community mental health system. Residential and crisis stabilization services are delivered by existing community mental health providers through the traditional delivery system. Participants are responsible for determining exactly which community-based services they want and by whom these services will be provided. An independent community advisory board comprised of service recipients, their significant others, and advocates guides the program. Participant recovery is being measured in a number ways, including productive days in the community (productive as defined by each individual), structured self-reports of

satisfaction with the program's delivery approach from participants, and structured self-reports about achievement of personal recovery goals and objectives. Standard objective measures are being used to evaluate individual outcomes that will include input from significant others and recovery coaches. The major difference in measurements between AMHSDC and the traditional system is the participant self-reports about personal recovery achievement and satisfaction with the total AMHSDC delivery system (www.floridasdc.info/Pages/Welcome.html).

Implementing a self-determination approach requires at least three major changes in the system. First, there needs to be a shift away from prescriptive, professionally designed treatment planning to individualized, consumer-authored recovery planning. In the developmental disabilities field, this has been called person-centered planning. Person-centered planning maximizes consumer choice. Second, financing mechanisms need to be redesigned to increase consumers' control of their own care. Third, the range of available choices needs to be expanded. These points are discussed below.

Step 2.1 Shift to person-centered planning.

Currently, professionals direct treatment planning. Plans are based on diagnostic labels and treatment guidelines that ignore the individualized nature of recovery. The Commission Report recommends “that each adult with a serious mental illness...have an individualized plan of care” and “Consumer needs and preferences should drive the type and mix of services provided” (Commission Report, p. 35). When people are allowed to fashion their own recovery goals based on their dreams, they are much more motivated to carry them out. In contrast, when their goals are set for them by professionals, they appear unmotivated.

The Western New York Care Coordination Program provides an example of the person-centered approach in which “the person’s dreams, interests, preferences, strengths, and capacities are explicitly acknowledged and drive activities, services, and supports.” The Program description further states, “services and supports are individualized and don’t rely solely on pre-existing models” (www.carecoordination.org).

Step 2.2 Shift to financing mechanisms that support increased consumer control.

Finance services and supports to allow money to follow the individual.

Current funding mechanisms are inflexible, medically based, and present many challenges to fundamental shifts in the system toward one that is person-centered and recovery-based. In contrast, the Commission Report recommends that “the funding for the plan should then follow the consumer, based on their individualized care plan” (p. 35). We describe two models here, but much more work needs to be done to insure that money follows the person and is used to purchase those services that are desired by the individual and that promote recovery.

In Florida, the Self-Directed Care Program, which covers four counties, has established individual budgets for 100 program participants through which they can select and purchase the services they want to fulfill their individual recovery plans. Payment is made through a fiscal intermediary by means of vouchers. Participants can select from a wide array of traditional and nontraditional services; the criterion is that the services must promote the individual's recovery. The program is utilizing a mix of Medicaid and State funds.

In New Hampshire, the plan is to shift some Department of Behavioral Health (DBH) funding to a "recovery bundle," which includes those services and activities that promote recovery directly through education, vocational training, supported employment, recreation, community involvement, additional treatment, and other activities to be defined. This is in addition to a separate "clinical bundle." Recovery services are nonmedical services that do not require supervision by a physician, and are expected to be reimbursable through Medicaid. Participants may use the assistance of a consumer advocate to develop individual budgets defining the use of available funds, subject to review by the case manager. Through this mechanism, DBH intends to empower consumers to take instrumental action on their own behalf toward their recovery goals. A project oversight group consisting of DBH, participating centers, and consumers will oversee implementation and make reports to all providers and interested parties (personal communication from Linda Paquette, New Hampshire Department of Behavioral Health).

The State of Michigan received a grant in 2003 to begin a consumer cooperative demonstration that would encourage groups of consumers and their families to pool economic resources to obtain the best set of services for their members. This approach (similar to a food-buying cooperative) is based on market-based incentives and the increase of consumer economic power (Barrie, 2003).

Finance consumer-run national and statewide technical assistance centers.

Technical assistance (TA) centers can play a vital role in the shift to services that are truly self-determining. Just as the NRI and SRIs are important in the development of policies that support self-determination, these TA Centers can provide the training and information to providers and consumers as needed to carry out person-centered planning, flexible funding such as individual accounts, and an expansion of consumer-run services.

Step 2.3 Expand the range of choices of services and supports available.

Expand peer-provided services.

The report of the Consumer Issues Subcommittee to the New Freedom Commission also recommended that peer support services be integrated into the continuum of community care and that public and private funding mechanisms be made sufficiently flexible to allow access to these effective support services. The Subcommittee proposed

that a carve-out from the Federal Community Mental Health Block Grant funding be established to support the integration of community-based peer support services within the continuum of community care: “We encourage the inclusion of billable peer services under the Medicaid Rehabilitation Option [as has been carried out in Georgia]” (www.mentalhealthcommission.gov).

To expand the range of service choices, the NRI Action Plan recommends increased consumer involvement in these four major peer roles:

Peer professionals. A peer professional is someone who has professional training (for example, as a psychiatrist, psychologist, nurse, or social worker), who has also recovered from a personal experience of mental illness, and who is open about his/her experiences. A peer professional combines both academic and experiential knowledge and brings both aspects to his or her work. By improving the supports for consumers entering professional schools and by recognizing recovery from mental illness as a positive asset, the field can be greatly enriched. The enthusiasm and knowledge of people who have recovered is a valuable and underutilized asset.

A 26-year-old man who had recovered from schizophrenia wrote to the NEC, “Since I have made a miraculous recovery, I want to go into the field, get my graduate degree in social work, and share my recovery process with as many schizophrenics as I can and help them recover, too” (personal communication, December 2003).

Peer specialists. A peer specialist is someone who has recovered or is in recovery (see above distinction between limited and genuine recovery) and who has received specialized training to provide peer support services. In a number of States, such as Georgia, programs have been developed in which peer specialists receive training and certification, and their services are reimbursable through Medicaid.

The Georgia Consumer Network proposed an idea for peer-led services, and the State Mental Health Authority formulated a plan for services led by professional consumers that would meet all the parameters of a Medicaid-financed service. During discussions with the Medicaid authority, it was determined that the State should shift its delivery practices from the Medicaid Clinic Option to the Rehabilitation Option in order to better facilitate the promotion of rehabilitation principles. Negotiations through the State planning process with the Federal Medicaid agency yielded results, and in July 1999, service delivery began. New peer support services as well as other more recovery-focused day services were made available. Georgia has the distinction of being the first State to gain approval from CMS to offer “Peer Supports” as a billable service in the State plan for Medicaid mental health services. On February 1, 2004, South Carolina became the second State to approve of peer support services as Medicaid billable services.

Peers as staff in consumer-run programs. Most States now have at least a few consumer-run programs. Some States, such as Michigan and New Hampshire, have

funded large numbers of them. Most consumer-run programs are drop-in centers, where people can come to spend time meeting others and participating in activities. Other examples of consumer-run programs include a smaller number of housing programs, job-finding programs, warmlines, and a few crisis centers. In all cases, people who participate in the programs have a major role in running them and making decisions about them. People who work in these programs are usually paid, with funding sources including State and local governments, private foundations, and individual donations. Two recent reviews of the literature (Davidson, Chinman, et al., 1999; Solomon & Draine, 2001) established that there is preliminary evidence to support the effectiveness of peer-run support services to help people with mental illnesses. Consumers in the consumer-run support centers had better social functioning than the ones in Community Mental Health Centers (Yanos et al., 2001).

The Ruby Rogers Advocacy and Drop-In Center in Somerville, MA, provides an example of a peer-run program. The Center, a freestanding consumer-run advocacy program, was started in 1984 and applied for funding from the Massachusetts Department of Mental Health. The Center's budget included funds for a part-time (eventually full-time) director, who was specified to be a person who had recovered from mental illness, as well as a number of part-time staff positions that enabled members to take on leadership roles while still being able to collect benefits. The Center provided informal peer counseling and a wide range of member-led activities that engaged the interest of members and went far beyond the typical "busy work" of traditional day treatment.

Funding and bureaucratic limitations continually created obstacles. Because the Center did not fit into any existing Department of Mental Health program description, there were a number of funding crises. Eventually the Center was put under the auspices of a professionally run program, limiting its autonomy. Nonetheless, the Ruby Rogers Center, along with literally hundreds of consumer-run drop-in centers around the country, provide models of how consumers/survivors take on leadership roles in helping their peers toward recovery.

Peers involved in mutual support. This is the most informal kind of peer support, and it can evolve into ordinary friendship. In addition to peer support that is provided on a one-to-one basis, informal networks of support involve larger numbers of people. For example, many people participate in support and discussion groups over the Internet. Every year, hundreds of people get together for the annual Alternatives Conference, which not only provides information and knowledge about peer support and other important learning experiences, but also gives people the opportunity to network informally.

Expand the use of personal assistance services for people with psychiatric disabilities.

In addition to services provided by peers, other models can increase consumer choice. A model that should be carefully examined is that of consumer-directed personal assistance services (PAS). PAS are widely available for people with physical and (to a

certain extent) developmental disabilities. In 1999, the National Blue Ribbon Panel on Personal Assistance Services stated:

...people with disabilities should have meaningful and informed choices regarding types of long-term services and supports they receive. This choice should include choice of setting (home vs. institution) in which long-term services are received. After this choice has been made, consumers should have control over the extent to which they will manage and direct those services. This emphasis on consumer choice and control is congruent with core American values that put a priority on personal independence and responsibility. (Independent Living Research Utilization Program of The Institute for Rehabilitation and Research, 1999)

The Commission recommended that PAS be available for a number of different population groups, including both those with physical disabilities and those diagnosed with mental illnesses. Nonetheless, the availability of PAS for people with psychiatric disabilities continues to be extremely limited.

In Oregon, the State Mental Health Authority runs the C-PASS program for people with psychiatric disabilities, which funds personal care services (PCS) through the Oregon Home and Community Based Waiver. Eligible individuals (who must be Medicaid recipients who live in independent settings and require assistance with basic life tasks) are eligible for up to 20 hours a month of PCS services. These services are consumer-directed and are received by approximately 300 individuals statewide. The consumer has the power to hire, train, and fire the personal assistant, and payment is by means of a voucher that is signed by the service recipient and paid by the State using Medicaid waiver funds. A study is underway in Oregon to analyze the ways in which consumers use these services, and to greatly increase the number of people taking advantage of them. Currently, only about 4.3 percent of eligible individuals statewide use the services (Anderson & O'Keefe, 2002).

PAS is only one methodology for making mental health services responsive to individual needs. It is being described in such detail here because it is a method which already has a long and successful track record for serving people with disabilities in a self-determined manner, and for which Medicaid funding is already available (although significantly underutilized for people with psychiatric disabilities).

Conclusion

In conclusion, we see that changing the mental health system from its dependency-oriented institutional thinking to one that is based on the principles of recovery will require a concerted effort of consumers and allies working to bring about changes in beliefs and practices at every level of the system. Without fundamental changes in the overall culture of the system, none of the most clever funding schemes or peer-run services will be significantly different from the traditional, institutional medical model approach. The President's New Freedom Commission report is a start in the right direction. However, to make the vision of the report a reality, a core of national and State level consumer leaders need to embrace it and be supplied with the resources to carry it forward. All stakeholders who believe in the recovery approach must join in alliances to enable the implementation of transforming activities that will make possible the Commission's vision of a system in which every person can recover.

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